



Affiliate stigma and caregiver burden in parents of children with epilepsy

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ABSTRACT

Objective: This study aimed to investigate the current status of affiliated stigma and caregiver burden among parents of children with epilepsy, analyze their correlation, and identify factors influencing affiliated stigma.

Methods: A cross-sectional survey was conducted among 194 parents of children with epilepsy who met the inclusion and exclusion criteria in Shenzhen City, Guangdong Province, China. Data were collected through questionnaires, including a demographic information sheet, an affiliated stigma scale, and a caregiver burden scale.

Results: The results revealed that parents of children with epilepsy experienced a moderate level of affiliated stigma, with an average score of 54.92 ± 10.44 . Similarly, caregiver burden scores fell within the moderate range, with an average score of 44.14 ± 16.02 . Factors influencing affiliated stigma scores included the frequency of epileptic seizures in children, the types of anti-epileptic medications taken by children, and the place of residence. The total caregiver burden score and scores in various dimensions (emotional, cognitive, and behavioral) of caregivers for epilepsy patients were positively correlated with the affiliated stigma score. Affiliated stigma was found to independently explain 21.3 % of the variation in caregiver burden.

Conclusion: In the future, healthcare professionals should develop targeted interventions for children with epilepsy and their parents to reduce affiliated stigma, decrease caregiver burden, and enhance the caregiving capabilities of parents of children with epilepsy. These measures are essential to improve the overall well-being of both parents and children affected by epilepsy.

1. Introduction

Epilepsy is a complex, chronic neurological disorder characterized by recurrent seizures resulting from abnormal neuronal activity in the brain (Neri et al., 2022). This condition transcends age boundaries, affecting individuals across the lifespan, with a notable prevalence among children. Research underscores the significance of epilepsy as a health concern, with a lifetime prevalence of 7.2 per 1000 individuals among children, approximately 5 % of whom will experience at least one epileptic seizure during their lifetime (Camfield and Camfield, 2015). This is especially pertinent in the context of children's health, as they are in a critical phase of neurodevelopment. The occurrence of epileptic seizures can profoundly impact cognitive and behavioral development, potentially elevating the risk of Sudden Unexpected Death in Epilepsy (Donner et al., 2017).

However, the repercussions of epilepsy extend beyond the affected children, casting a substantial psychological burden on their parents. Epileptic seizures, marked by their unpredictable nature, significantly

disrupt the self-perception of those affected (Rani and Thomas, 2019). Furthermore, misconceptions and societal stigmas surrounding epilepsy lead to what is known as "affiliate stigma" experienced by parents (Lee et al., 2020). Affiliate stigma encompasses the emotional strain indirectly felt by parents due to their association with the stigmatized label of epilepsy (Kassie et al., 2021). People may be discriminated against and devalued because these diseases. And they will take steps to avoid these pre-set situations, typically social isolation and concealment of children illness, which in turn brings negative effective on the quality of life and may enhance their feeling of stigma. This emotional burden often leads parents to avoid open discussions about their child's medical condition out of fear of social isolation. This, in turn, detrimentally affects the mental and physical well-being of parents and hampers the effective treatment and rehabilitation of the affected children (Kariuki et al., 2021; Benson et al., 2017).

Additionally, the care of children with epilepsy is a highly intricate task (Karakaş et al., 2022). Parents of these children shoulder a substantial burden of caregiving responsibilities, adversely affecting family

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functionality and the quality of parent–child relationships (Lavin et al., 2022; Lai et al., 2019). In 2018, the International League Against Epilepsy recognized the need to prioritize reducing affiliate stigma, emphasizing its direct impact on the treatment of children with epilepsy. However, existing research predominantly focuses on epilepsy patients themselves, with limited attention to the experiences of parents of children with epilepsy. Family caregivers are often referred to as “hidden patients,” as they may exhibit symptoms of caregiving stress, including emotional fluctuations, fatigue, headaches, physical pain, conflicts, and financial difficulties.

Caregiver burden in parents of children with chronic diseases, such as epilepsy, can result in mental health issues, ultimately affecting treatment adherence and the overall prognosis of the disease (Baulac et al., 2015). The impact of childhood epilepsy on families is a frequently overlooked issue in research and clinical practice (Vinkeles Melchers et al., 2018). In China, because of the influence of traditional Confucian concepts, more emphasis is placed on family units as well as parental responsibilities, and less community support is obtained due to different medical environments and the West, parents assume more responsibilities in the care of children with epilepsy, especially mothers, and studies have shown that the severity of disease in children with epilepsy is associated with maternal depression rates. At present, some people still misunderstand epilepsy disease, that epilepsy is devil upper body or infectious, these bring heavy mental stress to parents of children with epilepsy, increase their care burden, affect the prognosis of children with epilepsy and family stability, in previous studies to prove that gender, age, religion and other factors will affect the stigma of parents of children with epilepsy and caregiver burden to varying degrees (Yang, 2019). Therefore, this study seeks to delve deeper into the stigma experienced by parents of these children and the caregiving burden they carry. The research aims to explore the relationship between these two factors, analyze the determinants of stigma, and establish a more robust theoretical foundation for future interventions. This investigation holds the potential to provide fresh insights into the field of epilepsy, sparking innovative explorations to enhance the quality of life for affected children and their families (Gogou and Cross, 2022).

2. Methods

This cross-sectional study was carried out at the Children’s Hospital of Guangdong Province, China, spanning from May 2020 to June 2023.

2.1. Participants

The inclusion criteria were as follows: Parents of children aged 0–18 years who had been diagnosed with epilepsy by neurologists, were undergoing treatment at the Children’s Hospital of Guangdong Province, and were willing to participate in the survey. Parents who declined to provide consent, were illiterate, incapable of reading or completing the questionnaires, had a history of mental illness, severe physical ailments, or had recently experienced major life traumas were excluded. Additionally, parents of children with comorbid conditions involving epilepsy and other chronic diseases (e.g., heart disease, tumors, leukemia, congenital heart disease, diabetes) were also excluded due to potential influences on family functioning and caregivers’ mental well-being.

A total of 194 parents of children with epilepsy participated in this study. Prior to disseminating the questionnaires to parents of children with epilepsy, the researchers provided comprehensive explanations regarding the study’s objectives, significance, and content. They elucidated the requisites and guidelines for questionnaire completion, ensuring the research’s anonymity. Participants were instructed to carefully peruse the questionnaire instructions and respond truthfully. In instances of questions or uncertainties regarding the questionnaire or its items, the researchers promptly provided clarification and explanations. The estimated completion time for the questionnaire ranged from 10 to 20 min. To augment the questionnaire’s validity and authenticity,

researchers collected the completed questionnaires on-site. Data from the questionnaires were meticulously recorded, and questionnaires with more than 15 % of unanswered items were considered invalid. A thorough double-checking process was implemented to ensure data entry accuracy. All participants willingly joined the study and formally signed informed consent forms. This study was ethically approved by the hospital’s ethics committee (Ethical Approval Number: 2020032).

2.2. Questionnaires

Include baseline characters, caregivers’ affiliate stigma scale, and caregiver burden scale.

The baseline characters included demographic information, caregiver gender, educational level, religious beliefs, comorbid conditions, economic status, relationship with the patient, and place of residence, epilepsy-related information, including seizure frequency, types of medications used, and the method of medical payment.

The level of caregivers’ affiliate stigma was assessed using the Stigma Scale for Caregivers, originally designed to evaluate stigma in caregivers of individuals with mental illness or intellectual disabilities (Mak and Cheung, 2010). Mak introduced it into China and tested its reliability and validity in China’s national conditions (Mak and Kwok, 2010). The scale comprises 22 items distributed across three dimensions: emotional, behavioral, and cognitive. Participants rated each item on a 4-point scale, with scores ranging from 1 to 4, indicating “strongly disagree,” “disagree,” “agree,” and “strongly agree,” respectively. The Cronbach’s α coefficient for this study was 0.929, and the Cronbach’s α coefficients for the three dimensions ranged from 0.822 to 0.855, signifying the scale’s robust reliability.

The caregiver burden levels of the parents were assessed using the Caregiver Burden Scale (Zarit et al., 1980), designed by Zarit et al., translated into Chinese, and validated for reliability and validity by Wang Gang et al. This scale featured two dimensions: personal burden and responsibility burden, along with an overall perceived caregiving burden (Wang et al., 2008). The scale employed a 5-point rating system, ranging from 0 to 4, with 0 indicating “never” and 4 indicating “almost always.” The scale consists of two aspects of individual burden and responsibility, individual responsibility is composed of item 1,4,5,8,9,14,16,17,18,19,20,21, burden of responsibility by the entry, 2,3,6,11,12,13, item 22 is the overall evaluation for nursing, item 7, 10 and 15 are not grouped into two dimensions (Bauer, 2021). In this study, the total Cronbach’s α coefficient for the scale was 0.87, the Cronbach’s α coefficient for the personal burden dimension was 0.70, and the Cronbach’s α coefficient for the responsibility burden dimension was 0.83.

2.3. Statistical analysis

Count data were described by frequency and percentage, and Shapiro-Wilk test was used to test the normality of parental stigma score and caregiver burden score in children with epilepsy, and the results showed that the scores followed a normal distribution and were expressed as mean \pm standard deviation. Univariate analysis was subsequently performed using *t*-test and one-way ANOVA to test variables with significant statistical differences in parental stigma in children with epilepsy. Following univariate analysis, multivariable linear regression analysis was performed for variables with statistically significant differences to identify factors influencing parental stigma in epilepsy. Subsequently, linear regression and Pearson correlation analysis were performed between parental stigma scores and caregiver burden scores in children with epilepsy to explore the relationship between parental stigma and caregiver burden in children with epilepsy. $P < 0.05$ was considered statistically significant. Statistical analysis was performed using SPSS 26.0 software.

3. Results

3.1. Participant characteristics

In our study, we found that 93 children (47.9 %) were aged 0–8 years, and 101 children (52.1 %) were aged 9–18 years. The demographic distribution of children with epilepsy revealed that 52.58 % were male, while 47.42 % were female. Among the primary caregivers, mothers accounted for 78.35 %, while fathers represented 21.65 %. See [Table 1](#) for details.

3.2. Assessment of affiliate stigma in parents of children with epilepsy

This study unveiled variations in the levels of affiliate stigma experienced by parents of children with epilepsy. The total affiliate stigma score among parents averaged 2.50 ± 0.47 . This aggregate score was further deconstructed into emotional dimension (2.50 ± 0.52), cognitive dimension (2.57 ± 0.57), and behavioral dimension (2.43 ± 0.57). Detailed score breakdowns are presented in [Table 2](#), shedding light on the emotional, cognitive, and behavioral distress that parents may encounter when dealing with epilepsy. These scores provide foundational data to facilitate a deeper understanding of the impact of affiliate stigma on parents.

3.3. Assessment of caregiver burden in parents of children with epilepsy

The study findings demonstrated that the total caregiver burden

Table 1

Distribution the characteristics of children with epilepsy and their parents. From Children’s Hospital of Guangdong Province, China, May 2020 to June 2023. (n = 194).

Type		N (%)
Epileptic child’s age	0–8 years old	93 (47.9)
	9–18 years old	101 (52.1)
Epileptic child’s gender	Male	102 (52.58)
	Female	92 (47.42)
Primary caregiver’s gender	Father	42 (21.65)
	Mother	152 (78.35)
Caregiver education	Up to Junior High School	68 (35.05)
	High School or Technical Secondary School	63 (32.47)
	College and Undergraduate	59 (30.41)
	Graduate and Above	4 (2.06)
Residence	Rural	79 (40.72)
	Urban	68 (35.05)
	City	47 (24.23)
Religious	Yes	22 (11.34)
	No	172 (88.66)
Comorbid conditions	Yes	143 (73.71)
	No	51 (26.29)
Ketogenic diet	Yes	19 (9.79)
	No	175 (90.21)
Seizure frequency	No seizures in the past year	74 (38.10)
	One or two seizures per year	40 (20.62)
	Monthly seizures	40 (20.62)
	Weekly or daily seizures	40 (20.62)
Types of medications taken	0	44 (22.68)
	1	43 (22.16)
	2	33 (17.01)
	3 or more	74 (38.14)
Medical Payment Methods	Urban Medical Insurance	66 (34.02)
	Rural Cooperative Medical Care	63 (32.47)
	Out of Pocket	63 (32.47)
	Other	2 (1.03)

Abbreviation: N, number of cases.

Table 2

Distribution the affiliate stigma scores and caregiver burden score in parents of children with epilepsy, from Children’s Hospital of Guangdong Province, China, May 2020 to June 2023. (n = 194).

	Number of Items	Range	Total Score (M ± SD)	Item Mean (M ± SD)
Affiliate Stigma Total Score	22	0–87	54.92 ± 10.44	2.50 ± 0.47
Emotional Dimension	7	0–28	17.47 ± 3.52	2.50 ± 0.52
Cognitive Dimension	5	0–24	15.35 ± 3.42	2.57 ± 0.57
Behavioral Dimension	10	0–36	22.09 ± 4.95	2.43 ± 0.57
Caregiver Burden Total Score	22	0–88	44.14 ± 16.02	2.00 ± 0.73
Personal Burden	12	0–44	23.54 ± 8.22	1.96 ± 0.69
Responsibility Burden	5	0–24	11.33 ± 5.73	1.89 ± 0.95

M, mean; SD, standard deviation

score among parents of children with epilepsy averaged 2.00 ± 0.73 . This cumulative score was further categorized into personal burden (1.96 ± 0.69) and responsibility burden (1.89 ± 0.95). Detailed score specifics can be found in [Table 2](#).

3.4. Univariate analysis between affiliate stigma in parents of children with epilepsy and participant characteristics

The results underscored statistically significant differences in affiliate stigma scores based on different residential areas (all with $P < 0.05$). Parents residing in rural areas exhibited the highest affiliate stigma scores (2.26 ± 0.32), followed by urban areas (2.50 ± 0.35), while parents from cities reported the lowest scores (2.90 ± 0.57). Statistically significant differences in affiliate stigma scores were also observed based on the frequency of epileptic seizures and the types of epilepsy medications taken (all with $P < 0.05$). Those whose children had not experienced seizures in the past year reported the lowest affiliate stigma scores (2.29 ± 0.38), while the highest scores were reported for parents of children experiencing seizures on a weekly or daily basis (2.48 ± 0.34), followed by those with seizures occurring one or two times a year (2.49 ± 0.37), and those with monthly seizures (2.85 ± 0.58). Parents of children who were not receiving epilepsy medications had the lowest affiliate stigma scores (2.23 ± 0.36), while those with a single medication type (2.28 ± 0.30), two medication types (2.54 ± 0.36), and three or more medication types (2.76 ± 0.52) exhibited the highest scores. No statistically significant differences were identified for the child’s gender, the primary caregiver’s identity, the presence of medical payment methods, the presence of comorbid conditions, and the history of following a ketogenic diet (all with $P > 0.05$). Additional details are available in [Table 3](#).

3.5. Multivariable regression analysis of factors influencing affiliate stigma in parents of children with epilepsy

Drawing from the outcomes of univariate analysis, three independent variables were incorporated into the regression equation model: the types of epilepsy medications administered to the children, the frequency of epileptic seizures in children, and the place of residence. Compared with Types of Medications is 0, The Types of Medications is two stigma score increased by 0.25 units (β 0.25, 95 % CI 3.57 ~ 10.58, $P < 0.05$) and the Types of Medications is three stigma score increased by 0.54 units (β 0.54, 95 % CI 8.22 ~ 15.25, $P < 0.05$). Compared with Seizure Frequency is no seizures in the past year, One or two seizures per year stigma scores increased by 0.17 units (β 0.17, 95 % CI 31.32 ~ 7.92, $P < 0.05$), monthly seizures stigma scores increased by 0.16 units (β 0.16, 95 % CI 1.17 ~ 7.15, $P < 0.05$). Weekly or daily seizures stigma scores increased by 0.51 units (β 0.51, 95 % CI 7.98 ~ 16.89, $P < 0.05$). Compared with residence is rural, Urban stigma scores increased by 0.25 units (β 0.25, 95 % CI 2.96 ~ 7.88, $P < 0.05$) and city stigma scores

Table 3

Distribution the univariate analysis between affiliate stigma in parents of children with epilepsy and participant characteristics. From Children’s Hospital of Guangdong Province, China, May 2020 to June 2023. (n = 194).

Type	N	Scores (M ± SD)	Statistic*	P
Epileptic Child’s Gender			0.707	0.888
Male	102	2.52 ± 0.48		
Female	92	2.47 ± 0.47		
Primary Caregiver’s Gender			−0.790	0.518
Father	42	2.45 ± 0.51		
Mother	152	2.52 ± 0.49		
Caregiver education			0.789	0.467
Up to Junior High School	68	2.29 ± 0.36		
High School or Technical Secondary School	63	2.57 ± 0.42		
College and Undergraduate	59	2.66 ± 0.56		
Graduate and Above	4	2.50 ± 0.59		
Residence			36.918	< 0.05
Rural	79	2.26 ± 0.32		
Urban	68	2.50 ± 0.35		
City	47	2.90 ± 0.57		
Religious			1.224	0.482
Yes	22	2.61 ± 0.44		
No	172	2.48 ± 0.47		
Comorbid conditions			0.280	0.067
Yes	143	2.50 ± 0.51		
No	51	2.49 ± 0.35		
Ketogenic diet			1.385	0.176
Yes	19	2.64 ± 0.53		
No	175	2.48 ± 0.47		
Seizure frequency			16.473	< 0.05
No seizures in the past year	74	2.29 ± 0.38		
One or two seizures per year	40	2.48 ± 0.34		
Monthly seizures	40	2.49 ± 0.37		
Weekly or daily seizures	40	2.85 ± 0.58		
Types of medications taken			19.582	< 0.05
0	44	2.22 ± 0.35		
1	43	2.28 ± 0.30		
2	33	2.54 ± 0.36		
3 or more	74	2.76 ± 0.52		
Medical Payment Methods			0.712	0.515
Urban Medical Insurance	66	2.41 ± 0.49		

Table 3 (continued)

Type	N	Scores (M ± SD)	Statistic*	P
Rural Cooperative Medical Care	63	2.54 ± 0.45		
Out of Pocket	63	2.55 ± 0.51		
Other	2	2.43 ± 0.29		

Abbreviation: N, number of cases. M, mean; SD, standard deviation;

increased by 0.58 units (β 0.54, 95 % CI 9.80 ~ 17.90, $P < 0.05$). The adjusted R^2 value indicated that these variables collectively explained 44.5 % of the total variation in affiliate stigma among parents. For additional information, please refer to Table 4, and consult Table 5 for variable assignments.

3.6. Correlation analysis between caregiver burden and affiliate stigma in parents of children with epilepsy

Pearson correlation analysis was undertaken to investigate the relationship between caregiver burden scores and the various dimensions of the affiliated stigma scale. The results unveiled a statistically significant positive correlation between the total caregiver burden score and the different dimensions of affiliated stigma, encompassing the emotional dimension ($r = 0.388$, $P < 0.01$), cognitive dimension ($r = 0.414$, $P < 0.01$), and behavioral dimension ($r = 0.403$, $P < 0.01$). Caregiver burden was assessed across two dimensions: personal burden and responsibility burden, both of which displayed a positive correlation with the emotional dimension of affiliated stigma. For further insights, consult Appendix 1.

3.7. Multivariable regression analysis of factors influencing caregiver burden in parents of children with epilepsy

The three dimensions of affiliate stigma—emotional dimension, cognitive dimension, and behavioral dimension scores—were integrated into the regression equation model. The outcomes demonstrated that all three dimensions significantly predicted caregiver burden scores. The adjusted R^2 value suggested that the dimensions collectively elucidated 21.3 % of the total variation in caregiver burden. For more comprehensive details, please consult Table 6.

Table 4

Distribution the multivariable analysis of factors affecting stigma in parents of children with epilepsy. From Children’s Hospital of Guangdong Province, China, May 2020 to June 2023. (n = 194).

Variable	β	SE	95 %CI	t	P
Types of Medications Taken(ref = 0)					
Constant	49.00	1.38	46.59 ~ 51.17	35.35	< 0.05
one	0.05	1.97	−1.78 ~ 4.46	0.64	0.525
two	0.25	2.11	3.57 ~ 10.58	3.29	< 0.05
Three or more	0.54	1.75	8.22 ~ 15.25	6.67	< 0.05
Seizure Frequency (ref = No seizures in the past year)					
Constant	50.33	1.10	48.24 ~ 52.14	45.89	< 0.05
One or two seizures per year	0.17	1.91	1.32 ~ 7.92	2.35	< 0.05
Monthly seizures	0.16	1.84	1.17 ~ 7.15	2.28	< 0.05
Weekly or daily seizures	0.51	1.78	7.98 ~ 16.89	7.02	< 0.05
Residence (ref = Rural)					
Constant	49.62	1.00	48.09 ~ 51.13	49.50	< 0.05
Urban	0.25	1.47	2.96 ~ 7.88	3.64	< 0.05
City	0.58	1.64	9.80 ~ 17.90	8.59	< 0.05

Abbreviation: $R^2 = 0.445$, $F = 37.91$. Dependent variable: stigma score.

Table 5

Distribution of the independent variable assignments, from Children's Hospital of Guangdong Province, China, May 2020 to June 2023. (n = 194).

Independent variables	Assignment of Values
Residence	Rural = 000, Urban = 010, City = 001
Seizure Frequency	No seizures in the past year = 0000 One or two seizures per year = 0100 Monthly seizures = 0010 Weekly or daily seizures = 0001
Types of Medications Taken	0 types = 0000 1 type = 0100 2 types = 0010 3 or more types = 0001

Table 6

Distribution of the multivariable regression analysis of factors influencing caregiver burden in parents of children with epilepsy, from Children's Hospital of Guangdong Province, China, May 2020 to June 2023. (n = 194).

Variable	B	SE	β	t	P
Constant	4.909	5.652	–	0.869	0.386
Cognitive Dimension	1.061	0.418	0.226	2.536	0.012
Behavioral Dimension	0.451	0.322	0.139	1.4	0.163
Emotional Dimension	0.743	0.409	0.163	1.816	0.071

Abbreviation: $R^2 = 0.213$, $F = 17.144$.

4. Discussion

This study aimed to explore the experiences of affiliate stigma and caregiver burden among parents of children with epilepsy. The findings provide valuable insights into the challenges faced by caregivers and underscore the need for better support and intervention.

In 2018, the International League Against Epilepsy recognized the need to prioritize reducing affiliate stigma, emphasizing its direct impact on the treatment of children with epilepsy (Wilmschurst et al., 2018). The study reveals that parents of children with epilepsy experience a moderate level of affiliate stigma. This stigma is most pronounced in the cognitive dimension, suggesting that parents are acutely aware of societal misconceptions surrounding epilepsy. Several factors contribute to this stigma, including public misunderstanding, bias against epilepsy, and the emotional reactions of fear, social isolation, and discrimination (Nabi Amjad et al., 2017). Additionally, the lack of developed healthcare systems related to childhood epilepsy in China places significant caregiving responsibilities on parents, impacting their physical, mental, familial, economic, social, and functional aspects (Tanaka et al., 2018). The study also highlights the influence of the place of residence, with parents from rural areas exhibiting higher levels of affiliate stigma (Reilly et al., 2018). In rural areas, due to the influence of traditional culture and the lack of corresponding science popularization, it is easier to have a wrong understanding of epileptic diseases and stigmatize epileptic diseases, resulting in parents of children with epilepsy in rural areas more likely to avoid medical treatment, social isolation and other symptoms. At the same time, the lack of medical resources in rural areas also affects the treatment of children with epilepsy, which further aggravates the condition, increases the frequency of seizures, and further increases the stigma of parents. Interventions should focus on health education, knowledge dissemination, and psychological support for parents. Healthcare professionals should also assess and address the psychological well-being of parents.

In this study, the frequency of epileptic seizures in children significantly affects affiliate stigma in parents. Parents of children who experience seizures frequently report higher levels of stigma. This aligns with previous research indicating that increased seizure frequency can lead to uncertainty and concerns about social image and public experiences, intensifying affiliate stigma (Kanemura et al., 2016). It's crucial for healthcare professionals to offer guidance and support to parents,

particularly when the frequency of seizures is high, to help them cope with the challenges associated with their child's condition.

The study shows that the types of epilepsy medications taken by children are associated with varying levels of affiliate stigma in parents. Parents of children taking multiple medications tend to experience higher levels of stigma. This suggests that these children may have more severe and refractory epilepsy, which can be harder to control and is often associated with other neurological conditions. Healthcare professionals should provide specific guidance on daily living and medication management, emphasizing the importance of consistent medication intake.

The study also evaluates the caregiver burden experienced by parents of children with epilepsy, revealing a moderate level of burden (Bakula et al., 2021). Significantly, it identifies a positive correlation between affiliate stigma and caregiver burden, indicating that higher levels of stigma are associated with increased caregiving responsibilities (Nelson and Robert, 2019). This highlights the necessity for customized caregiving interventions aimed at alleviating affiliate stigma and reducing caregiver burden. Implementation of strategies such as caregiver intervention groups and peer support activities can enhance the psychological well-being of parents and ultimately enhance the quality of life for both children with epilepsy and their families (Evelt et al., 2021). Furthermore, the research demonstrates that affiliated stigma independently explains 21.3 % of the variation in caregiver burden, signifying its predictive value in determining the level of caregiver burden within families of epilepsy patients.

This study provides critical insights into the experiences of parents of children with epilepsy, shedding light on affiliate stigma and caregiver burden. The findings underscore the importance of targeted interventions and support to enhance the well-being of parents and children alike, ultimately improving their quality of life.

5. Conclusion

In conclusion, this study delved into the challenges faced by parents of children with epilepsy concerning affiliate stigma and caregiver burden. The findings underscore the significant impact of factors such as affiliate stigma, seizure frequency, and the types of medications used, particularly for parents of children with epilepsy residing in rural areas or dealing with high seizure frequencies and multiple medications. These findings serve as a reminder that healthcare providers and policymakers should pay greater attention to parents of children with epilepsy, providing relevant support and resources to reduce their affiliate stigma, alleviate caregiver burden. Additionally, for parents of children with epilepsy, more intervention measures can be considered, such as psychological support, education, and social assistance, to help them better confront this challenge and improve their quality of life.

6. Limitation

This study has certain limitations, including a relatively small sample size, geographical constraints, and its cross-sectional nature. Moreover, the samples collected in this study were during the COVID-19 epidemic period, and we did not explore whether COVID-19 affected this study. Future research could involve larger sample sizes and cross-regional comparisons to further validate these findings and explore other potential influencing factors. It is our hope that through more in-depth research and targeted interventions, the lives of parents of children with epilepsy can be improved, their burdens lightened, and their overall well-being enhanced. The scales used in this paper (affiliate stigma scale, and burden scale), although already tested in a group of parents of children with other diseases, have not been applied in this group of children with epilepsy, which is one of the limitations of this paper. Second, the scale used in this paper does not give clear criteria to distinguish the score level.

Author contributions

Article Writing: Xingyanan Wang was responsible for composing the article.

Data Collection: Xiaoqin Tian and Jinghua Ye were tasked with the collection of data.

Data Analysis: Fangping Wang conducted data analysis to derive meaningful insights.

Experimental Design: The experimental design was under the purview of Xiaocui Guo.

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Appendix 1. . Distribution the correlation analysis of caregiver burden and affiliate stigma in parents of children with epilepsy, from Children's Hospital of Guangdong Province, China, May 2020 to June 2023. (n = 194)

Variable	Caregiver Burden Score	Personal Burden	Responsibility Burden	Emotional Dimension	Cognitive Dimension	Behavioral Dimension
Caregiver Burden Score	1					
Personal Burden	0.960**	1				
Responsibility Burden	0.921**	0.800**	1			
Emotional Dimension	0.388**	0.369**	0.364**	1		
Cognitive Dimension	0.414**	0.408**	0.378**	0.574**	1	
Behavioral Dimension	0.403**	0.353**	0.409**	0.680**	0.674**	1

Abbreviation: **, $P < 0.01$.

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Conflicts of interest

The authors declare no conflicts of interest.

CRediT authorship contribution statement

Xingyanan Wang: . **Jinghua Ye:** Methodology. **Xiaoqin Tian:** Project administration. **Fangping Wang:** Writing – original draft. **Xiaocui Guo:** .

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The data that has been used is confidential.